

### IN THIS ISSUE

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## Introducing our Kidney Health Ambassadors – Wyatt and Jenna Crockett

It is with much excitement we introduce our Kidney Health New Zealand Ambassadors. Jenna and Wyatt are passionate about raising awareness and promoting organ donation.

Jenna received a kidney transplant from her friend in 2015 and is a ball of energy and enthusiasm and wants to do what she can to raise awareness. Wyatt has recently retired from the All Blacks with 71 caps and Crusaders where he played 102 games for the team. Wyatt knows only too well the impact kidney disease can have on a family and wants to share his story in an effort to raise awareness and help others.



You can visit our website, Facebook Page or Instagram account to watch Jenna and Wyatt share their experience living with kidney disease.

<https://fb.me/kidneyhealthnz>

<https://www.instagram.com/kidneyhealthnz/>

## Celebrating 40 years of Kidney Health in New Zealand

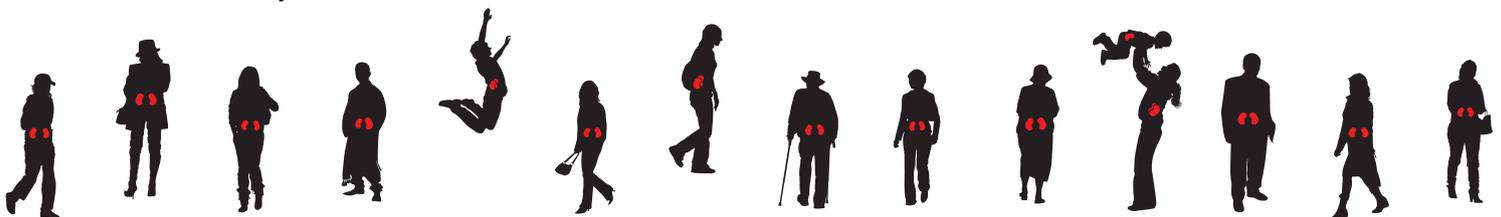
As it is our 40th year of operation, I have used this opportunity to do some research into the history of the organisation, it has been fascinating to read through the first constitution and rule book written with the establishment of the, then National Kidney Foundation of New Zealand. I thought I'd share some of these excerpts;



Kidney Health  
Prevention • Support • Research NEW ZEALAND

*"The Foundation was established as a result of the efforts of a number of people who had either experienced, or observed close relatives or friends, the suffering and distress which can result from disease and malfunction of the kidneys or the urinary tract"*

The National Kidney Foundation was founded in 1979 by members of the Terrace End Rotary Club of Palmerston North and had its headquarters in Wellington. The main aims of the Foundation were: to fund research, raise community awareness about diseases of the urinary tract, support increasing facilities for home dialysis and encourage kidney donation and transplantation. Rotary clubs throughout New Zealand provided support for the establishment of local NKF branches, which numbered 15 by 1986.



- In 1976 there were 70 patients with irreversible kidney failure accepted for treatment, nearly all of whom were under 60 years old.
- In 1985 there were approximately 150 people on dialysis and the annual cost of dialysis treatment was estimated at \$6,000 for home dialysis and for hospital based dialysis \$14,000, making the annual cost to treat dialysis patients in New Zealand to \$1,500,000.

In comparison according to ANZDATA 2016 approximately 4500 New Zealanders have end-stage kidney disease (ESKD), and this number is increasing by 5% each year. The prevalence of treated dialysis and transplanted patients (forms of Renal Replacement Therapy – “RRT”) has risen by 250% over the last 15 years. Expenditure on RRT accounts for between 1 to 2 percent of the total public health expenditure. Dialysis currently costs New Zealand over \$150 million each year and is approximately 3 times more expensive than transplantation on a per patient per year basis.

## 🌀 Farewell and thank you to our CEO and retiring Board members

In December we bid farewell to Max Reid who had been CEO for KHNZ over the last four years, thank you for your hard work and commitment to the organisation, we wish you all the very best in your new role based in Dunedin.

We also farewell three long serving Board members of KHNZ as part of the rotation policy. Our thanks go to Dave Henderson, Nora van der Schriek and Humphry Rolleston for their time and dedication to Kidney Health New Zealand, your commitment to ensure our work, to improve and promote the wellbeing of people affected by kidney disease was a priority is appreciated, and we look forward to continuing our work with the four new Board members.

## 🌀 Introducing our new Board members

### David Shearer

David brings to KHNZ governance and executive experience across commercial, not-for-profit, government and education organisations, as well as time spent as an independent consultant.

Significant roles include CEO of award-winning not-for-profit SARINZ, Workforce Strategist at ChristchurchNZ, establishing Australia’s first onshore teacher placement/recruitment business for Protocol Teachers, and Director of MBA and Executive programmes at University of Canterbury.



David is the Director of SYNED, a consultancy offering advisory, governance, education and recruitment services to emerging and established leaders. In this role he gets to live his purpose to connect people and organisations to ideas and opportunities, so they grow, thrive and positively impact our community.

Outside work David is Chair of the Workbridge HR and Remuneration Committee and a member of Canterbury MBA Graduate Association. When he’s not diving for Pāua with family in Wainui he is an avid art collector, curator of antique maps (future-proofing for when google maps fail!), lazy runner and an average tennis player looking for an excuse to travel with his teenage family.

David was born with obstructive uropathy and has chronic kidney disease stage 4. A regular user of renal services and a strong supporter of KHNZ he feels it’s a privilege to have the opportunity to tangibly contribute to KHNZ mission and give back to the renal community.

## John Kearns

I am a 55 year old Maori New Zealander, born in Auckland with whakapapa to the far north iwi of Te Rarawa and Ngati Kuri. I was first diagnosed with renal failure in June 1984, started haemodialysis in September 1986 and received my first transplant, donated by my elder sister, in March 1987. I subsequently received two more deceased donor transplants in 2002 and 2015. Altogether I have done 8 and half years of in-centre, self-care and nocturnal home haemodialysis.



My first transplant lasted until August 2000 whereupon I dialysed at Greenlane Self Care for 2 years. In September 2002, I received my second transplant, which unfortunately failed in March 2010 due to Membranous glomerulonephritis. For my third round of dialysis, I trained and did nocturnal home haemodialysis for nearly six years until Christmas Day 2015 when I received my third and current transplant.

With 34 years' experience as a renal patient, I believe I can contribute and help to improve our renal service from a patient's perspective. To this end I have been a Consumer Representative on the National Renal Transplant Leadership Team since November 2014 and a board member for Auckland District Kidney Society since August 2016. Recently in November 2018 I was accepted on to the board of Kidney Health New Zealand. Back in 1989 I also helped form the New Zealand Transplant Games Association and was in the first New Zealand team to compete at the World Transplant Games in Singapore.

On a professional basis, I have had a 30 year seagoing career and have been fortunate enough to have worked on a diverse range of vessels from Tall Ships, Sailing Yachts, Dredges and Offshore Support Vessels to Super Yachts in both the commercial and private sectors. For the past seven years, I have been working as a shipbroker which requires me to liaise with clients in New Zealand and from around the world on the sale and purchase of commercial and recreational vessels. I also undertake valuations on a variety of vessels, including Bulk Carriers, Container Ships, Dredges and Yachts. On occasion, I also work with the New Zealand High Court on vessels that are arrested on the New Zealand coast.

Over the past 34 years of dealing with renal failure, I feel I have been extremely privileged to have received three transplants and undertaken dialysis for some eight and half years while staying relatively well; enabling me to receive my transplants. I am also fortunate that I was born in New Zealand, a country with a great renal service, which has enabled me to get married, have three beautiful daughters, two grandchildren, continue to work and of course, enjoy life.

## Traci Stanbury

Traci's journey into health services began when her son was diagnosed with a rare kidney disease thirteen years ago (ARPKD). Since then she has become a staunch advocate for child health and organ donation, as well as a community representative at a local, regional and national level. Traci completed a Master of Health Sciences with a focus on improving the well-being of child health and improving the current NZ rates of organ donation.



She has served on the Canterbury DHB Family Advisory Committee, the South Island Child Health Strategic Leadership Alliance and the Health Quality and Safety Commission's Consumer Network. In 2016 Traci was recognised by the Ministry of Health's annual Volunteer Awards for her services to Child Health.

Traci brings 20 years of marketing experience to her board role and currently works at the University of Canterbury, marketing education and health programmes and research.

## Natalie Brown

My name is Natalie Brown and I was born and have lived my life in Dunedin.

I attended Otago Girls High School and have a Bachelor in Commerce, majoring in Accounting from Otago University and I am a Chartered Accountant and member of the Institute of Directors.

My various jobs and roles have been with IRD, KPMG, Anderson Lloyd and consulting and contracting to Meridian Energy, University of Otago and Dunedin City Holdings Limited to name a few.



I received a Renal Transplant from my brother in Perth, on the 27th July 1994, the day Otago beat the Springboks. I was extremely lucky my only brother was compatible with me and this meant I only spent 9 months on Peritoneal Dialysis. My fistula proved problematic and so I gave PD a try which worked well for me working full time bringing up my teenage boys on my own.

I have been a member of the Otago Kidney Society for over 20 years holding various positions, which have included Secretary and Treasurer the latter position I hold at present.

I have my own consulting business and have worked in various roles mainly in the Contracting, Consulting area for Companies such as Meridian Energy, The University of Otago and Dunedin City Holdings Limited.

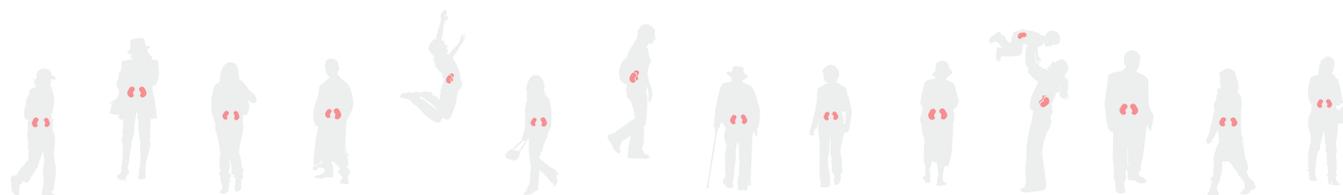
My husband and I have a blended family with 4 children and 8 grandchildren between us.

I am now using my skills to help in the areas of Kidney Health which is an obvious passion of mine to make a difference to the wider kidney community.

## From the Acting CEO/National Education Manager

It's been a whirlwind couple of months, I am loving the challenge of this role and learning a few new skills along the way. As I mentioned in our first E news just before Christmas, changes in an organisation offers the opportunity to review our activities and we look forward to engaging with our stakeholders and supporters in doing this.

We have been working on several projects with a particular focus on consumer engagement and ways we can improve the service we provide, what you would like to see from KHNZ, what can we do better and in turn letting us know a little more about our supporters.



As part of our review we have a very brief survey we would like you to fill in, either via the attached link, the link on the home page of our website, or by returning the completed survey in the prepaid envelope enclosed with this newsletter.

<https://www.surveymonkey.com/r/L86YCRD>

Your feedback is very important to us and helps us to ensure we are achieving the best outcomes for people affected by kidney disease.

We would really appreciate your support with this as alongside the Consumer council, you can help us with informing our strategic plan.

Our Consumer Council will be meeting at the end of March to discuss issues for renal patients, although the meeting is reserved for the members, we always welcome hearing from you should you have concerns or suggestions, so please feel free to contact us anytime.

Our advocacy work continues in a variety of areas, including the issue of Away from Home Dialysis, as many of you will know it is incredibly difficult to access haemodialysis when looking to travel both within New Zealand and/or overseas. Renal units do their best to accommodate requests from visitors, but this is proving to be increasingly difficult due to capacity issues. And with the loss of the Taupo Holiday Home and, more recently, the Hawkes Bay Mobile campervan there are now only two Mobile haemodialysis facilities remaining for those able to dialyse independently, although these are well used, these options are limited to those who are familiar with the Fresenius 4008b machines. There is much work to be done to improve the current situation, including discussions with DHBs about the importance of renal service planning, promoting home-based modalities and including the provision for away from home dialysis, KHNZ will continue to advocate in this space and look forward to being able to report on progress in the near future.

As always we are looking at ways to raise awareness of kidney disease, recently I was fortunate enough to be part of the inaugural launch of the Lyttleton Health Hub where I provided free kidney health checks and information, this new initiative has been supported by the local GP who has donated her Medial Centre facility on the first Saturday of every month for health groups to offer free services to the community. This is a strengths based collective, using a collaborative approach in promoting Community Action in partnership with Primary Care, KHNZ looks forward to supporting this wonderful initiative in the future.

## Holly's Story

*Holly is a New Zealander now living in the north of England, she has a blog where she shares her journey with kidney disease the following is her most recent contribution which I think is worth sharing, with her consent.*

I was diagnosed eight years ago this week. I remember sitting in the clinic with my parents and having loads of information thrown at us. At that stage there were far more questions than answers. I had absolutely no idea what most of it meant then, let alone what it would continue to mean eight years later.



It's been both so much worse and so much better than I ever expected.

I remember leaving the hospital and going out for dinner with my family that night, where my cousin took this picture. I'm laughing and smiling, but my mind is going a million miles an hour. Everyone else knew I'd been to an appointment, but we didn't talk about what had happened. I think I was still at the point of worrying about things which now seem like huge overreactions. "Would I have to leave my job?", "Would the treatment work?", "Could I die?"

No.

Yes, kind of.

No, not yet anyway.

I'm a fairly forward-looking person. Even though I worry about the future, I don't often spend huge amounts of time sitting thinking about things which have happened previously, even though they're the things which got me here.

I recently saw a discussion online about what "type" of person you are when you deal with your illness? Are you resentful? Or are you grateful?

I don't know whether I'm both or neither. I'm certainly not exclusively one or the other.

Of course, I hate that I'll never really be a "healthy person", even if I can do a good impression of one most days. I still have to think about taking medication, drinking enough water, avoiding germy people, monitoring myself for indications I might be getting sick, and all that other stuff. At some point this kidney will fail or wear out and more healthcare decisions will have to be made. Sometimes I do find myself wondering where I'd be if I hadn't got sick. How far would I have gone in life? Would I be more successful? Happier? I wonder whether I have been held back, and I just don't realise what I'm missing.

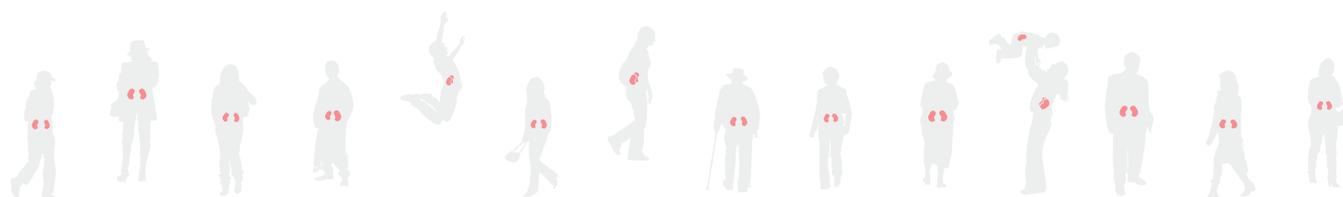
But equally, as cliched as it sounds (*so much so that I almost want to stop typing this and punch myself in the face instead!*) – it could be so much worse. I know I'm lucky to have always lived in countries with excellent healthcare. If there's any such thing as a perfect time to be diagnosed with a chronic illness, I think I found it. I know I'm lucky to not have had to deal with chronic illness as a child or teenager, and to get through my education without disruption. I'm fortunate that I was diagnosed with enough time to have treatment to delay my disease progression, and that that delay meant we could do far more pre-dialysis and pre-transplant planning than many others are able to. I also know I'm lucky to have had the opportunity to be part of positive, inspiring things as a result of my illness. I've had experiences I wouldn't swap for anything. I've met people I can't imagine my life without.

It sounds silly to say that even if I could, I'd never want to go back and live my life as it "should" have been without kidney disease in it, but I don't know whether I would or not. I think it's easy to immediately say "*Of course I wish I'd never got sick!*", but I think the further away you get from the actual point of change; the moment of diagnosis or accident or whatever, and the more life moves on, the more complicated this question becomes. Life fills in the gap between your "old life" and the one you have now. No doubt, some horrible things occur, but, sometimes surprisingly, so do good things, maybe things that wouldn't have happened otherwise.

Today, I might miss my old life and be desperate to go back and live it again. Tomorrow I could feel the complete opposite. It's like walking on a tightrope equally likely to fall off either side. Because we're human, it's never going to be as simple as a choice between totally resenting the life you have and choosing to be wholly grateful for it.

To follow Holly's blog use the link below:

<http://www.secondhand-life.com/about/>





## World Kidney Day 2019

Celebrated every year on the second Thursday of March, World Kidney Day (WKD) is the global campaign that aims at increasing awareness of the importance of our kidneys to our health and of reducing the impact of kidney disease and its associated problems worldwide.

Early diagnosis, prevention and delay of progression are sustainable options to reduce costs and consequences of kidney disease for individuals and countries. Yet, barriers to available, accessible, adequate and quality kidney care persist.

In New Zealand alone the number of people with some form of Chronic Kidney Disease is estimated to be more than 400,000, World Kidney Day on Thursday 14th 2019 is an opportunity to call on everyone to advocate for concrete measures in every country to improve kidney care, this includes:

- Encourage and adopt healthy lifestyles (access to clean water, exercise, healthy diet, tobacco control. Many types of kidney diseases can be prevented, delayed and / or kept under control when appropriate prevention measures are in place.
- Make screening for kidney diseases a primary healthcare intervention including access to identification tools (e.g. urine and blood tests). Screening of high-risk individuals and early diagnosis and treatment is cost effective to prevent or delay end-stage kidney diseases.
- Ensure kidney patients receive basic health services they need (e.g. blood pressure and cholesterol control, essential medications) to delay disease progression without suffering financial hardship.
- Call for transparent policies governing equitable and sustainable access to advanced health care services (e.g. dialysis and transplantation) and better financial protection (e.g. subsidies) as more resources become available. Breaking down socioeconomic barriers and expanding access to comprehensive services in order to meet the needs of the population is essential to guarantee equitable kidney care and increase quality.

There are activities planned around the country including the Walk for Kidneys happening in Kerikeri and Whangarei, in conjunction with Northland DHB renal services, and at the other end of the country the Otago Kidney Society is also planning a walk taking place on Sunday March 17th. In Auckland Hospital the renal team are offering free kidney health checks in the Foyer of the hospital. There will be many other activities happening.

## How can YOU support World Kidney Day?

This March we need your help to recognise World Kidney Day. This year's theme is "Healthy Kidneys for Everyone Everywhere". A great opportunity to raise awareness about the importance of kidney health in your community.

Raising awareness will make kidney health more "recognisable" and encourage support both financially and help to broaden the work KHNZ does. By raising awareness, you will increase our ability to produce reliable information for kidney patients, advocate for people affected by kidney

disease, work with healthcare professionals in the fight against kidney disease, and as we work to achieve better kidney health for all New Zealanders.

Kidney Health New Zealand can support you in your efforts. A couple of simple but effective ways of raising awareness are:

- Share our social media posts with your network
- Tell your kidney health story, either to us or on social media
- Put posters around your community
- Approach businesses to put a collection bucket on the counter
- Get your workplace/school or local community group involved
- Post your activities on your social media (and tag us in)
- Remember simple works best

Get in touch if you would like help with your activities. We want you to succeed so might be able to help with ideas, we also have resources that you can use to support you.

How will raising awareness help kidney patients? Awareness of kidney disease will encourage people to get their kidneys checked. It will increase early diagnosis of kidney disease. Early diagnosis will, in many cases, provide a better chance of avoiding dialysis, leading to better survival rates. You could save a life.

For us, raising awareness will help us to reach more people. Health professionals, especially those working in Primary care, people at increased risk of kidney disease, more funders, and more fundraisers. It will help us to assist patients, increase early diagnosis, and remain financially sustainable to continue to improve the lives of people affected by kidney disease.

With your help we can achieve more.

For ideas on raising awareness and fundraising check out our website [www.kidneys.co.nz](http://www.kidneys.co.nz). If you need more help get in touch [jacqui@kidneys.co.nz](mailto:jacqui@kidneys.co.nz).

Don't have time or not able to raise awareness? But you want to support our work you can donate to Kidney Health New Zealand this World Kidney Day!

To donate, complete the form included with this newsletter or visit our website and click the donate button. Your donation will help us to do more.

***Together we will increase early diagnosis of kidney disease and, by doing so, can potentially save lives.***

**Yes, I want to help in the fight against Kidney Disease and support Kidney Health New Zealand!**

I/we would like to donate:  \$100  \$50  \$30  Other: \_\_\_\_\_

Payment type:  Cheque (made payable to Kidney Health NZ)  Mastercard  Visa

Card number:

Card expiry date:     /     /     Name on card: \_\_\_\_\_

I would like:  A receipt for my donation  Information about gifting to Kidney Health in my will

Information about kidney donation/transplants  To become a member of Kidney Health NZ

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Please return this form to Kidney Health New Zealand, PO Box 20072, Bishopdale, Christchurch.